

Current evidence and future priorities for reproductive health data linkage in the UK: scoping review and dataset mapping

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Objectives

Researchers are currently limited in their ability to understand reproductive health across the life course and across health-care services due to unlinked data. We aimed to map the current landscape of reproductive health data linkage in the UK, identify existing reproductive health datasets, and explore challenges faced by those seeking to use them.

Methods

First, we conducted a scoping review of five databases to identify publications using reproductive health data linkage among UK participants. Data was extracted to capture details relating to study characteristics and what, how, and why data was linked. Second, we undertook expert stakeholder consultations with 11 policy makers, clinicians, and researchers who work across a range of reproductive health topics and regions of the UK. These interviews were used to map existing reproductive health data resources, understand the challenges faced in the current data landscape, and explore priorities for a linked reproductive health data resource.

Results

Of 7,291 studies identified from the search, we found 272 studies linking reproductive health data, predominantly utilising routinely available health data to study reproductive cancers (n=129) and maternal and child health (n=92). Among the included studies, fewer focused on preconception, abortion, menopause, and contraception (n=36 total). Linkage methodologies were poorly reported and there was minimal public involvement. Through our expert consultations and review, we identified 247 existing UK reproductive health datasets. Experts highlighted gaps in questions they could currently answer on fertility, pregnancy loss, menopause, and menstrual pain, and difficulties understanding healthcare journeys across the life course without linkage across different settings of care. Stakeholders also wanted linkage to nuanced

data on deprivation, ethnicity, and migration to better understand marginalised groups' experiences.

Conclusions

UK research using linked reproductive health data currently contains inequalities in the topics and populations represented. Further efforts to create a linked reproductive health data resource, informed by public mandate and created using robust linkage methods, would enable researchers to fill data gaps, examine inequalities, and explore reproductive health trajectories.

